

FETAL ALCOHOL SPECTRUM DISORDERS

The Basics



SAMHSA
Fetal Alcohol Spectrum Disorders
Center for Excellence



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
www.samhsa.gov



Understanding Fetal Alcohol Spectrum Disorders

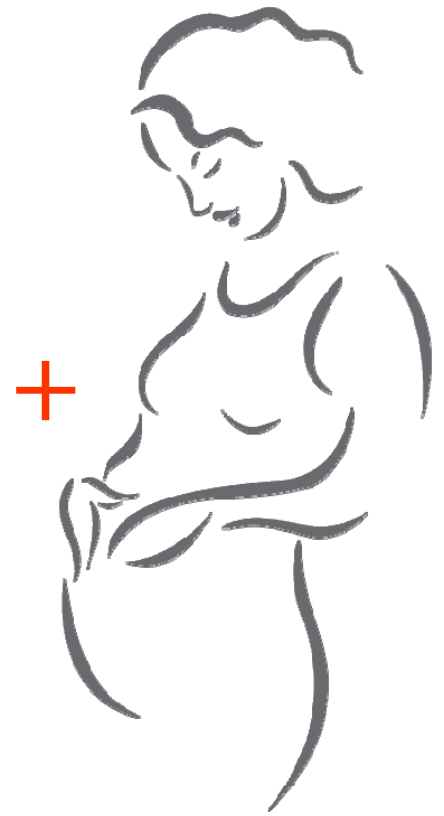
This section includes:

- Fetal Alcohol Spectrum Disorders (FASD)
- Terminology
- FASD Facts
- Cause of FASD
- FASD and Alcohol
- Alcohol and Women
- FASD and the Brain
- Number of People With an FASD

Fetal Alcohol Spectrum Disorders (FASD)



- Umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy
- May include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications
- Not a diagnosis





Terminology

- Fetal alcohol syndrome
 - Term first used in 1973 by Drs. Smith and Jones at the University of Washington
 - One of the diagnoses used to describe birth defects caused by alcohol use while pregnant
 - A medical diagnosis (760.71) in the International Classification of Diseases (ICD)

Terminology



Pregnancy



+

Alcohol



May result in



- Fetal alcohol effects (FAE)
- Alcohol-related birth defects (ARBD)
- Alcohol-related neurodevelopmental disorder (ARND)
- Partial FAS (pFAS)

FASD Facts



- 100 percent preventable
- Leading known cause of preventable mental retardation
- Not caused on purpose
- Can occur anywhere and anytime pregnant women drink
- Not caused by biologic father's alcohol use
- Not a new disorder





Cause of FASD

- The sole cause of FASD is women drinking alcoholic beverages during pregnancy.
- Alcohol is a teratogen.

“Of all the substances of abuse (including cocaine, heroin, and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus.”

—IOM Report to Congress, 1996

FASD and Alcohol

- All alcoholic beverages are harmful.
- Binge drinking is especially harmful.
- There is no proven safe amount of alcohol use during pregnancy.



FASD and Alcohol



- Binge = 4 or more drinks on one occasion for a women, 5 or more for a man
- Drink = 12 ounces of beer, 5 ounces of wine, or 1.5 ounces of hard liquor



=



=



Size Matters



**One
Unit**



Beer

12 oz

**One
Unit**



**1 small
glass of
wine**

5 oz

**One
Unit**



**1 single
measure
of spirits**

1.5 oz

**One
Unit**



**1 small
glass of
sherry**

3.5 oz

**One
Unit**



**1 single
measure
of aperitifs**

2.5 oz

Size Matters



12 oz.

VS.



16 oz.

Alcohol and Women



- If a woman is pregnant, it does not matter what form the alcohol comes in.
 - Wine spritzers, alcohol pops
 - Beer
 - Wine coolers
 - Light beer, nonalcoholic beer





FASD and the Brain

- Prenatal alcohol exposure causes brain damage.
- Effects of FASD last a lifetime.
- People with an FASD can grow, improve, and function well in life with proper support.

FAS and the Brain

Permission to use photo on file.

Normal brain of baby 6 wks old

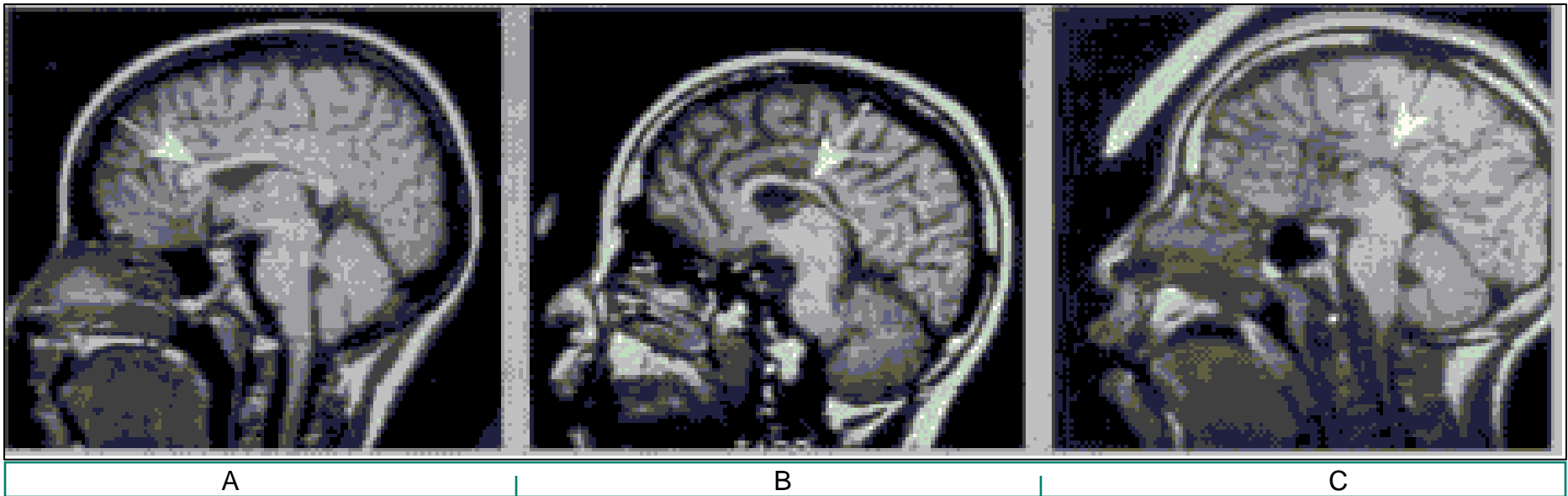


Brain of baby same age with FAS



Photo courtesy of Sterling Clarren MD

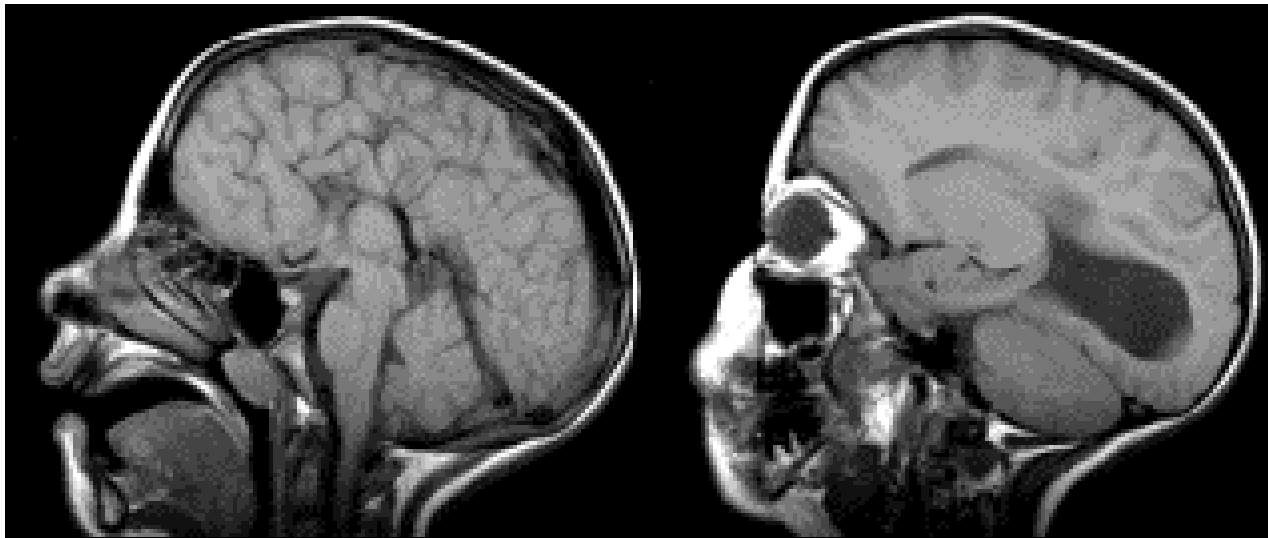
FAS and the Brain



A. Magnetic resonance imaging showing the side view of a 14-year-old control subject with a normal corpus callosum; **B.** 12-year-old with FAS and a thin corpus callosum; **C.** 14-year-old with FAS and agenesis (absence due to abnormal development) of the corpus callosum.

Source: Mattson, S.N.; Jernigan, T.L.; and Riley, E.P. 1994. MRI and prenatal alcohol exposure: Images provide insight into FAS. *Alcohol Health & Research World* 18(1):49–52.

FAS and the Brain



A

These two images are of the brain of a 9-year-old girl with FAS. She has agenesis of the corpus callosum, and the large dark area in the back of her brain above the cerebellum is essentially empty space.

Source: Mattson, S.N.; Jernigan, T.L.; and Riley, E.P. 1994. MRI and prenatal alcohol exposure: Images provide insight into FAS. *Alcohol Health & Research World* 18(1):49–52.

Number of People With an FASD

- No one knows for certain how many individuals are born each year with an FASD.
- No one knows how many individuals are living with an FASD.



Photo property of SAMHSA.



Prevention and Risk Reduction

This section includes:

- Prevention Is the Only Solution
- Talk About Alcohol Use
- Who Needs To Know
- Raise Awareness in Schools
- Raise Awareness in the Community

Prevention Is the Only Solution

- Ask all women of childbearing age about alcohol use:
 - Ask routinely at every medical appointment.
 - Ask at appointments in various systems.
 - Ask in a nonjudgmental manner.
 - Use effective screening tools.
 - Ask about possible prenatal exposure.



Photo courtesy of Microsoft.

Talk About Alcohol Use



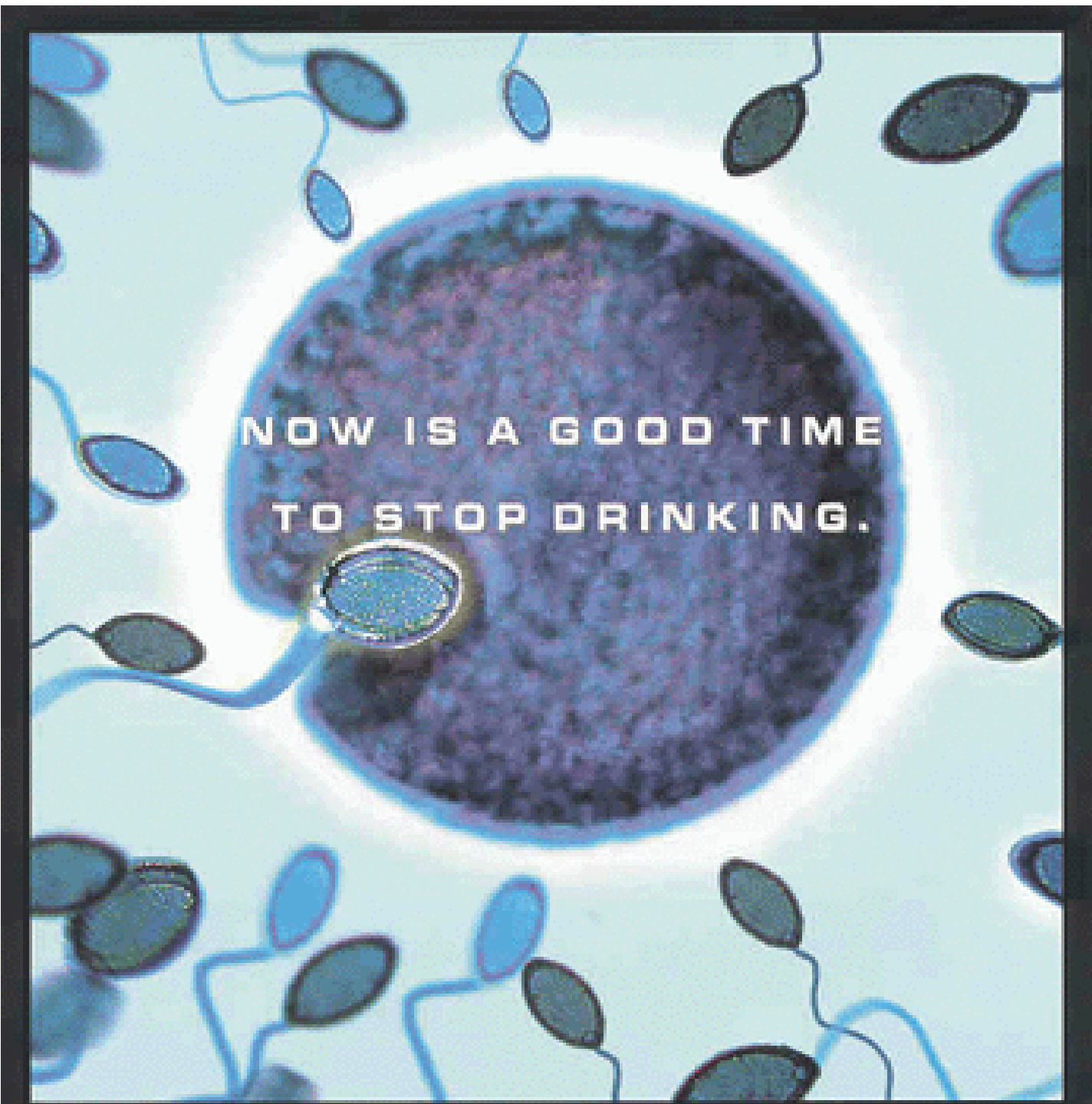
- Talk about the effects of alcohol on an individual and on a fetus:
 - Begin at an early age, such as elementary school.
 - Indicate that stopping drinking at any time during pregnancy will help the fetus.



**Convey the message: If you're pregnant, don't drink.
If you drink, don't get pregnant.**



DO NOT TAKE THE RISK



DO NOT TAKE THE DRINK

Who Needs To Know

- Women of childbearing age?
- Women who have a history of alcohol or other drug use?
- Women who are at risk?
- Teenagers?
- Men?
- **EVERYONE!**



Raise Awareness in Schools



- Ask the school to put up posters about drinking and pregnancy.
- Include information about FASD in health, science, and physical education classes.

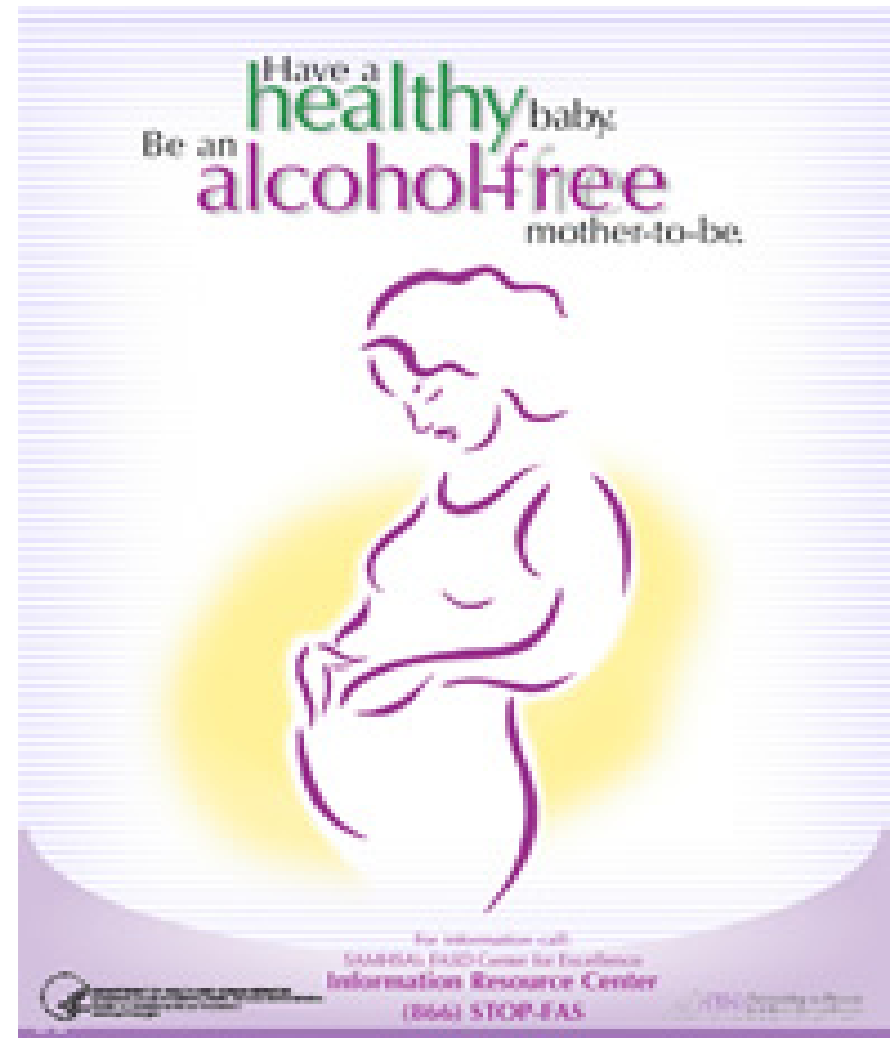


- Hold an assembly to talk about the effects of alcohol on a person and on a baby.

Raise Awareness in the Community



- Post FASD information in doctors' offices, treatment centers, and community centers.
- Promote FASD Awareness Day (September 9). Visit www.fasday.com for information.
- Focus attention on FASD. You can help the entire community.





Symptoms and Difficulties of FASD

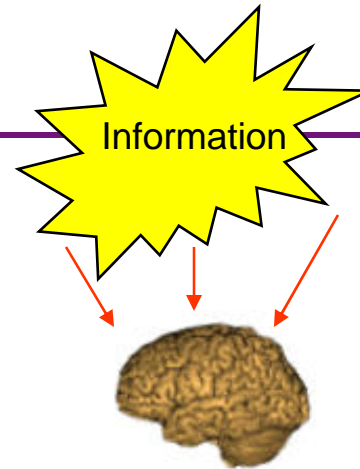
This section includes:

- Overall Difficulties for Persons With an FASD
- Primary Disabilities of Persons With an FASD
- Typical Difficulties for Persons With an FASD
- Secondary Disabilities of Persons With an FASD
- Factors Associated With Reduced Secondary Disabilities

Overall Difficulties for Persons With an FASD



- Taking in information
- Storing information
- Recalling information when necessary
- Using information appropriately in a specific situation



Primary Disabilities of Persons With an FASD



- Lower IQ
- Impaired ability in reading, spelling, and arithmetic
- Lower level of adaptive functioning; more significantly impaired than IQ



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Streissguth, et al. (1996)

Typical Difficulties for Persons With an FASD

Sensory Integration Issues

- Are overly sensitive to sensory input
 - Upset by bright lights or loud noises
 - Annoyed by tags in shirts or seams in socks
 - Bothered by certain textures of food
- Have problems sensing where their body is in space (i.e., clumsy)

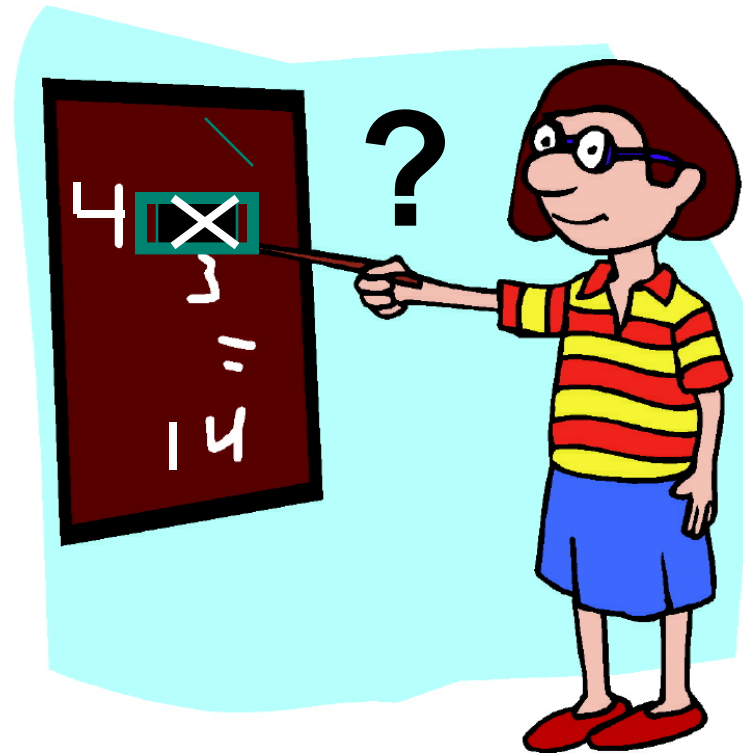


Typical Difficulties for Persons With an FASD



Memory Problems

- Multiplication
- Time sequencing



Typical Difficulties for Persons With an FASD

Information Processing Problems

- Do not complete tasks or chores and may appear to be oppositional
- Have trouble determining what to do in a given situation
- Do not ask questions because they want to fit in

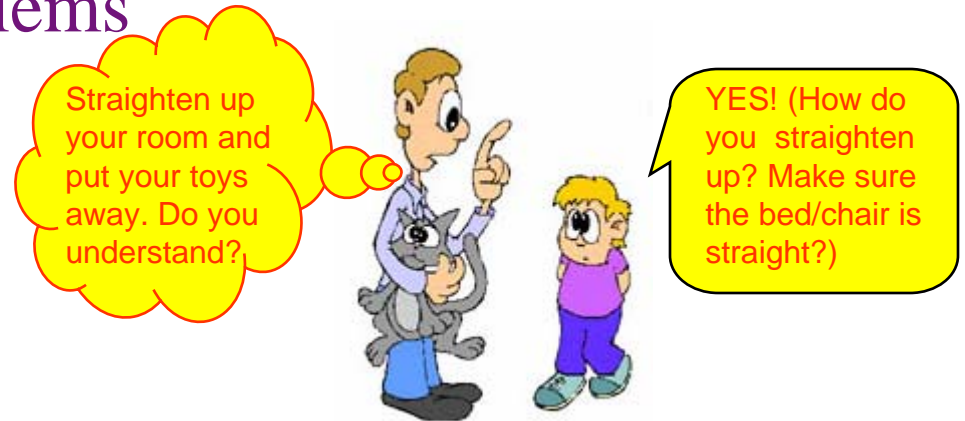


Typical Difficulties for Persons With an FASD



Information Processing Problems

- Say they understand when they do not
- Have verbal expressive skills that often exceed their level of understanding
- Misinterpret others' words, actions, or body movements
- Have trouble following multiple directions



Typical Difficulties for Persons With an FASD



Executive Function Deficits

- Go with strangers
- Frequently do not respond to point, level, or sticker systems
- Repeatedly break the rules
- Have trouble with time and money
- Do not learn from mistakes or natural consequences
- Give in to peer pressure





Typical Difficulties for Persons With an FASD

Self-Esteem and Personal Issues

- Function unevenly in school, work, and development
- Experience multiple losses
- Are seen as lazy, uncooperative, and unmotivated
- Have hygiene problems

Typical Difficulties for Persons With an FASD



Multiple Issues

- Cannot entertain themselves
- Have trouble changing tasks
- Do not accurately pick up social cues



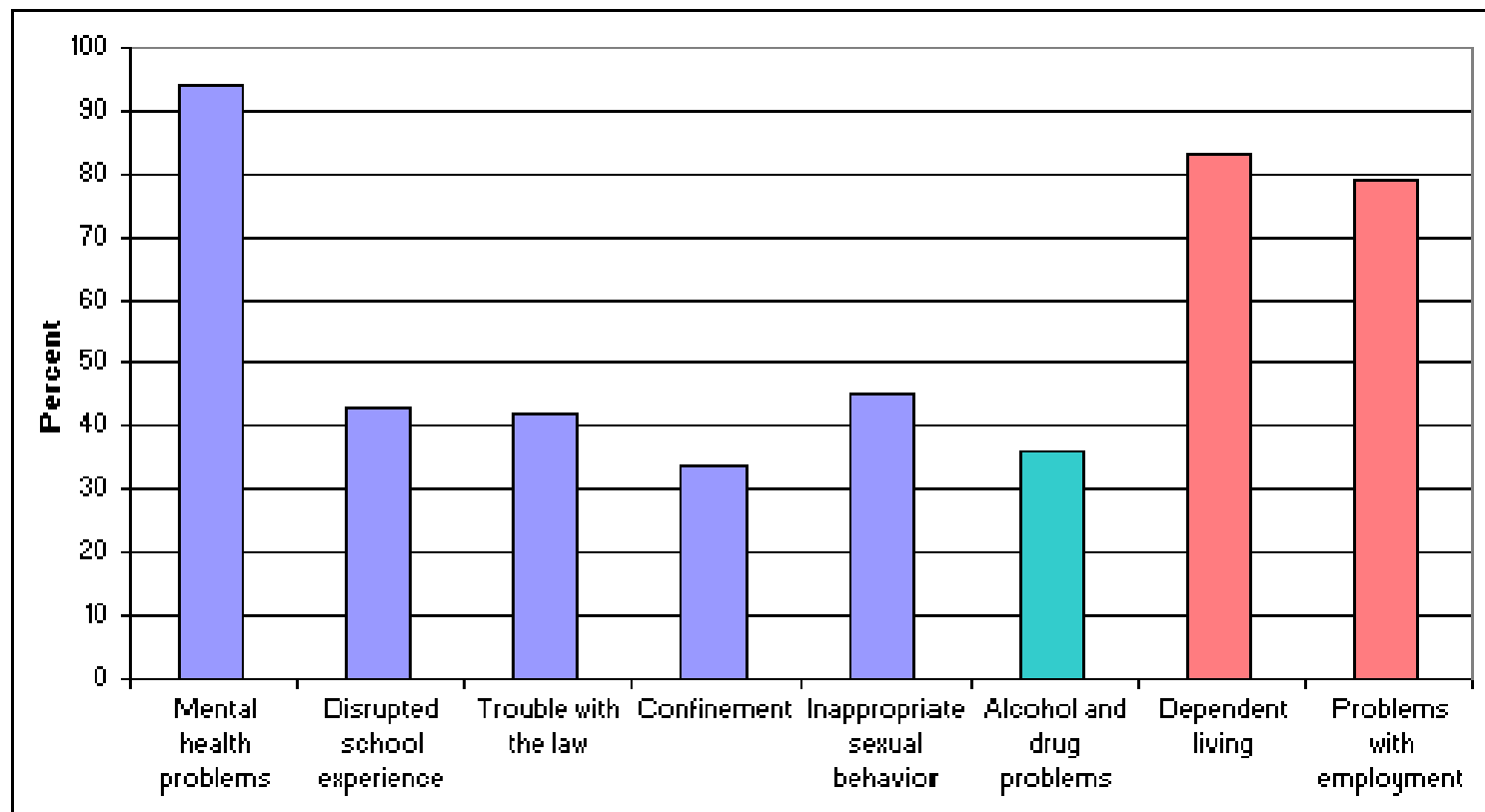


Secondary Disabilities of Persons With an FASD

- Mental health issues
- Disrupted school experience
- Trouble with the law
- Inappropriate sexual behavior
- Confinement in jail or treatment facilities
- Alcohol and drug problems
- Dependent living
- Employment problems

Secondary Disabilities of Persons With an FASD

Percent of Persons With FAS or FAE Who Had Secondary Disabilities



◆ = Age 6+

◆ = Age 12+

◆ = Age 21+



Factors Associated With Reduced Secondary Disabilities

- Stable home
- Early diagnosis
- No violence against oneself
- More than 2.8 years in each living situation
- Recognized disabilities
- Diagnosis of FAS
- Good quality home from ages 8 to 12
- Basic needs met for at least 13 percent of life

Streissguth, et al. (1996)



Diagnosis

This section includes:

- Diagnosing Fetal Alcohol Syndrome
- Differential Diagnosis of Features of FAS
- FASD and Mental Health Disorders
- Risks to a Child of Not Accurately Identifying and Treating FASD
- Risks to an Adult of Not Accurately Identifying and Treating FASD
- Benefits of Identification and Treatment

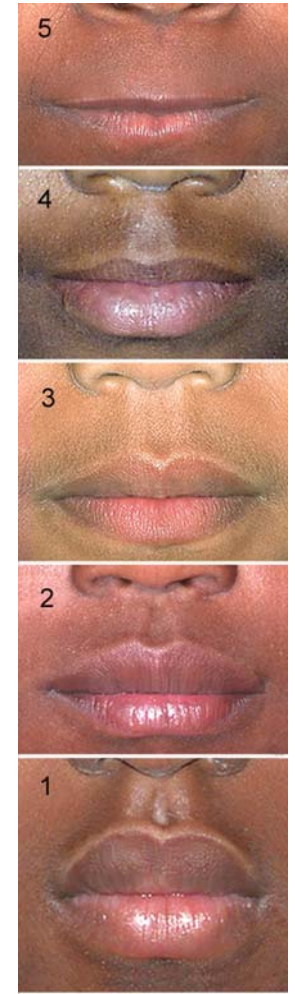
Diagnosing Fetal Alcohol Syndrome

- Prenatal maternal alcohol use
- Growth deficiency
- Central nervous system abnormalities
- Dysmorphic features
 - Short palpebral fissures
 - Indistinct philtrum
 - Thin upper lip

Source: Astley, S.J. 2004. *Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code, Third Edition*. Seattle: University of Washington Publication Services, p. 114.



Lip-Philtrum Guide 1
Caucasian



Lip-Philtrum Guide 2
African American



Differential Diagnosis of Features of FAS

- Differential diagnosis is very important because:
 - Many syndromes can cause features that look like FAS.
 - Facial features alone cannot be used to diagnose FAS.

FASD and Mental Health Disorders

- Prenatal alcohol exposure may lead to severe behavioral, cognitive, and psychiatric problems.
- FASD is not a psychiatric disorder.
- FASD can co-occur with a mental health or substance abuse disorder.

DSM-IV



Risks to a Child of Not Accurately Identifying and Treating FASD



- Loss of family
- Increased substance use
- Premature death



Photo courtesy of Microsoft.



Risks to an Adult of Not Accurately Identifying and Treating FASD

- Unemployment
- Jail
- Loss of family
- Premature death
- Homelessness
- Increased substance abuse

Benefits of Identification and Treatment



- Helps decrease anger and frustration for individuals, families, providers, and communities by helping them understand that negative behavior results from the disability and is not willful
- Helps people with an FASD succeed by focusing on why they have trouble in certain programs
- Helps improve outcomes
- Helps prevent future births of children with an FASD





Treatment

This section includes:

- General Issues With FASD
- Intervention Issues
- Systems of Care for Persons With an FASD
- Economic Costs of FAS



General Issues With FASD

- Often undiagnosed among persons without FAS facial features
- More difficulties seen in those without FAS facial features and with higher IQs
- Adaptive functioning more impaired than intelligence



Intervention Issues

- Failure in traditional mental health treatment programs
 - People with an FASD may know what they need to do but cannot follow through
 - Caregivers with unrecognized FASD often labeled neglectful, uncooperative, or sabotaging treatment because they do not follow instructions
- Limited FASD-specific treatment services

Systems of Care for Persons With an FASD



- Health
- Education
- Social and community services
- Legal and financial services



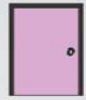
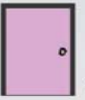














Systems of Care



Many Doors, No Master Key: Resources Needed for Brandon, Age 1-2 Years

Health

 Pediatrician	 Feeding Specialist
 Neurologists (2)	 Nutritionist
 Pediatric Ophthalmologist	 High-Risk Infant Clinic
 Audiologist	 FAS Diagnostic Clinic
 Otolaryngologist	 Lab and X-Ray Services
 Pharmacy	 Surgeons
 Medical Supply Providers	 Pulmonologist
 Gastroenterologist	 Respiratory Therapist






Education

 Physical Therapist
 Speech/Language Pathologist
 Infant Educator
 Cultural Recreational Therapy (e.g., drumming)
 Birth-3 Program: Occupational Therapist, Speech/Language Pathologist, Teacher, Aide, Play Therapist

Social and Community Services

 Local Indian Child Welfare Advisory Committee
 Tribal Social Worker
 Child Welfare/Case Worker
 Tribal Council
 Respite Providers
 Foster Care System

Legal and Financial Services

 SSI
 Medicaid
 Guardian Ad Litem
 Judge-Foster Care Issues
 Attorneys for Birth Parents



~ About 40 service providers

Economic Costs of FAS

- FAS alone cost the United States more than \$4 billion in 1998.
- The average lifetime cost for each child with FAS is \$2 million.

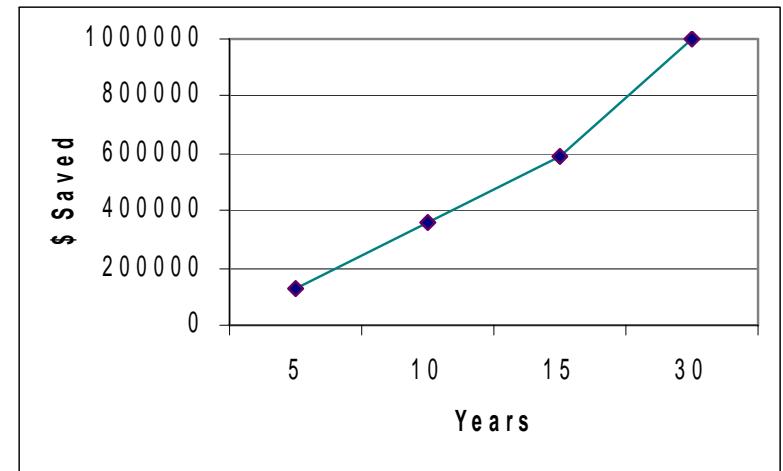
- \$1.6 million for medical care services
- \$0.4 million for loss of productivity



Economic Costs of FAS



- One prevented case of FAS saves:
 - \$130,000 in the first 5 years
 - \$360,000 in 10 years
 - \$587,000 in 15 years
 - More than \$1 million in 30 years



Increased savings
through prevention



Outcomes

This section includes:

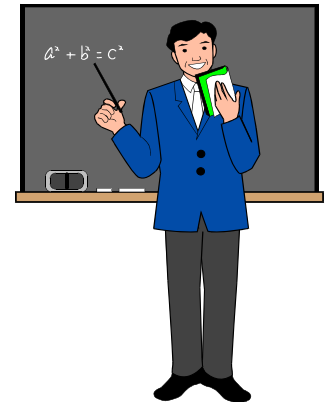
- Strategies To Improve Outcomes for Persons With an FASD
 - Strategies for Sensory Integration Issues
 - Strategies for Memory Problems
 - Strategies for Information Processing Problems
 - Strategies for Executive Function Deficits
 - Strategies for Self-Esteem and Personal Issues
- Strengths of Persons With an FASD
- Paradigm Shift

Strategies To Improve Outcomes for Individuals With an FASD

- Ask about possible prenatal alcohol exposure at intake.



- Educate families and providers about FASD.



- Ask about substance use during medical appointments.



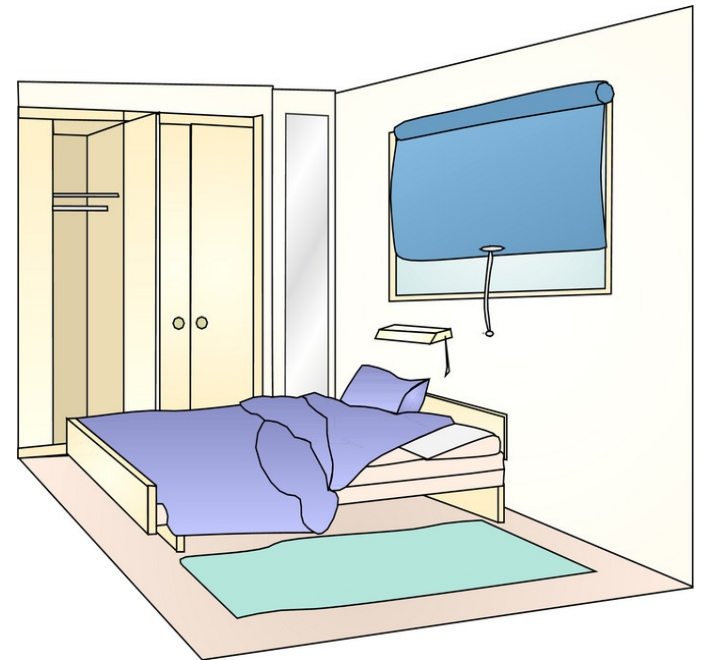
- Have a thorough diagnostic workup.

Strategies To Improve Outcomes for Individuals With an FASD



Strategies for Sensory Integration Issues

- Simplify the individual's environment.
- Provide a lot of one-to-one physical presence.
- Take steps to avoid sensory triggers.



Strategies To Improve Outcomes for Individuals With an FASD



Strategies for Memory Problems

- Provide one direction or rule at a time and review rules regularly.
- Use a lot of repetition.



Strategies To Improve Outcomes for Individuals With an FASD



Strategies for Information Processing Problems

- Check for understanding.
- Use literal language.
- Teach the use of calculators and computers.
- Look for misinterpretations of words or actions and discuss them when they occur.



Strategies To Improve Outcomes for Individuals With an FASD

Strategies for Executive Function Deficits

- Use short-term consequences specifically related to the behavior.
- Establish achievable goals.
- Provide skills training and use a lot of role playing.



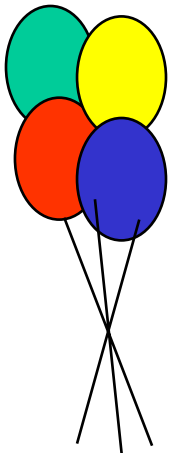
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Strategies To Improve Outcomes for Individuals With an FASD



Self-Esteem and Personal Issues

- Use person-first language (e.g., “child with FAS,” not “FAS kid”).
- Do not isolate the person.
- Address issues of loss and grief.
- Do not blame people for what they cannot do.
- Set the person up to succeed.



Strengths of Persons With an FASD



- Friendly
- Likable
- Desire to be liked
- Helpful
- Determined
- Have points of insight
- Not malicious



Dubovsky, Drexel University College of Medicine (1999)

Strengths of Persons With an FASD



- Cuddly and cheerful



- Happy in an accepting and supportive environment
- Loving, caring, kind, sensitive, loyal, and compassionate

- Energetic and hard working
- Fair and cooperative



- Spontaneous, curious, and involved

Permission to use photos on file.

Strengths of Persons With an FASD



- Highly verbal



- Highly moral—deep sense of fairness

- Kind with younger children and animals

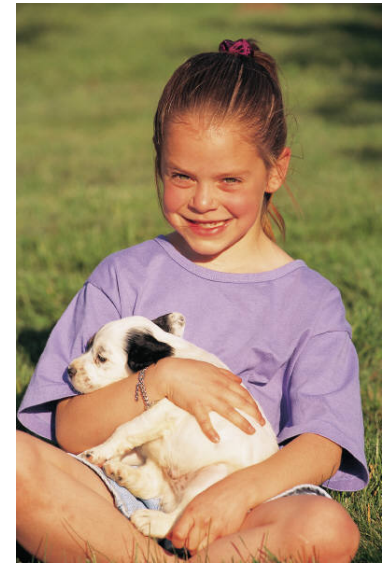


Photo courtesy of Microsoft.

- Able to participate in problem solving with appropriate support

Strengths of Persons With an FASD



- Build on strengths of persons with an FASD, such as giving them opportunities to help in the classroom.



Photo courtesy of Microsoft

- Use teaching strategies that focus on strengths.
- Find jobs that use the person's strengths.



Paradigm Shift

“We must move from viewing the individual as failing if s/he does not do well in a program to viewing the program as not providing what the individual needs in order to succeed.”

—Dubovsky, 2000



Resources

- SAMHSA FASD Center for Excellence:
fasdcenter.samhsa.gov
- Centers for Disease Control and Prevention FAS Prevention Team: www.cdc.gov/ncbddd/fas
- National Institute on Alcohol Abuse and Alcoholism (NIAAA): www.niaaa.nih.gov/
- National Organization on Fetal Alcohol Syndrome (NOFAS): www.nofas.org
- National Clearinghouse for Alcohol and Drug Information: ncadi.samhsa.gov
- These sites link to many other Web sites.